

### Introduction

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# Setting Priorities in Arthritis Care: Care III Conference

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**ABSTRACT.** The disparity between supply and demand in arthritis services can lead to delays in diagnosis and access to effective treatments. The focus of 2005 CARE III Conference was to develop a research agenda to improve care for people with arthritis. Topics included models of care, nonpharmacological/nonsurgical interventions for arthritis, and issues around study design, outcome measures and knowledge translation and exchange. Seven priority areas emerged from the discussion: (1) Develop new, innovative arthritis care strategies; (2) Adapt and implement effective service models to address local needs; (3) Understand factors related to successful team care; (4) Match patients' needs with appropriate care models; (5) Design new or improve outcome measures for participation and quality of life; (6) Foster partnerships in sharing research evidence; and (7) Address needs for training and quality assurance. (J Rheumatol 2006;33:1891–4)

#### Key Indexing Terms:

MODELS OF CARE

NONPHARMACOLOGICAL TREATMENT

ARTHRITIS

The overarching goal of the CARE III Conference was to develop an actionable research agenda to improve care for people with arthritis. CARE III extended the work from the previous CARE Conferences<sup>1,2</sup> and from the 2004 Frontiers in Inflammatory Joint Diseases Conference<sup>3</sup>. Topics included models of care, nonpharmacological/nonsurgical interventions for arthritis, and issues around study design, outcome measures and knowledge translation and exchange (KTE). Seventy-seven delegates attended, including rheumatology opinion leaders, researchers, patients, healthcare administrators, and research trainees, representing adult and pediatric communities in North America and Europe.

We designed several pre- and post-conference activities to engage the rheumatology community. First, about 3 months before the conference, all delegates were assigned to one of 3 facilitated online discussion groups (models of care, research designs, and outcome measures). Second, we developed an online survey to gather patient opinions about important issues

while receiving care<sup>4</sup>. Both the discussion groups and the survey were used to guide discussion at the conference. Third, we published editorials in relevant journals<sup>5,6</sup> to generate attention about care research in the arthritis community. Finally, shortly after CARE III, we held workshops at the American College of Rheumatology/Association of Rheumatology Health Professionals meeting and Canadian Physiotherapy Association Congress to disseminate the outcome.

On the last day of CARE III, attendees were asked to participate in group discussions about the direction and priorities of care research. In this introduction we summarize the 7 priority areas that emerged from the discussion, which are presented in no particular order.

The present series comprises 5 additional articles, 3 of which summarize intense discussion at the sessions on models of care, research designs, and outcome measures<sup>7–9</sup>. The remaining articles outline 2 unique views about the future direction of research. In the first, Petersson<sup>10</sup> discusses the need for multidisciplinary team care and outlines an agenda to study the process of team development and functioning. In the second report, Vliet Vlieland, *et al*<sup>11</sup> challenge the feasibility and the need for team care for everyone and argue that future research should focus on the development and evaluation of alternative care delivery models.

### CARE III: RECOMMENDED PRIORITIES FOR RESEARCH AND EDUCATION (Table 1)

#### To develop and evaluate new, innovative arthritis care strategies

A shortage of specialized healthcare practitioners (rheumatologists, nurses, and rehabilitation therapists) and facilities is

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*Abbott Laboratories has provided unrestricted educational grants to all CARE Conferences. CARE III is also supported by The Arthritis Society, Canadian Institute of Health Research / Institute of Musculoskeletal Health and Arthritis, The Public Health Agency of Canada, and Canadian Arthritis Network.*

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Table 1. Care III research and education priorities.

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Develop and evaluate new, innovative arthritis care strategies
<ul style="list-style-type: none"> <li>• Study methods that identify individuals with arthritis in the community</li> <li>• Develop models to facilitate timely access to treatment</li> <li>• Develop strategies for longterm monitoring</li> </ul>
Adapt and implement effective service models to address local needs
<ul style="list-style-type: none"> <li>• Support local needs assessments and environmental surveys to assess the suitability of a service model for local use</li> <li>• Support local projects to implement effective health service delivery models</li> </ul>
Understand factors related to successful team care
<ul style="list-style-type: none"> <li>• Understand the effect of different communication models on team cohesiveness</li> <li>• Identify health disciplines that are equipped or can be “retooled” to provide effective interventions</li> <li>• Understand the impact of “place” (i.e., hospital, clinic, home, virtual place) on the delivery of care</li> </ul>
Match patients’ needs with appropriate care models
<ul style="list-style-type: none"> <li>• Identify patients who are the most suitable for a specific model of care</li> <li>• Evaluate health service delivery models with respect to effectiveness, costs, patient satisfaction, and applicability at various stages of the disease</li> <li>• Support exploratory analyses of longitudinal data (e.g., demographic information, disease and health outcomes and the use of health services) collected in the clinical setting to study trends of patient characteristics and care needs</li> </ul>
Design new or improve outcome measures for participation and quality of life
<ul style="list-style-type: none"> <li>• Understand concepts of participation and quality of life</li> <li>• Develop a core set of measures for care research</li> </ul>
Foster partnerships in sharing research evidence
<ul style="list-style-type: none"> <li>• Include knowledge translation strategies in research projects</li> <li>• Understand the roles of stakeholders in the dissemination and uptake of research evidence</li> <li>• Understand patients’ roles in preparing and reviewing research grants</li> <li>• Develop strategies to improve the effectiveness of patient participation in research</li> </ul>
Address needs for training and quality assurance
<ul style="list-style-type: none"> <li>• Develop standards for the core and advanced curricula in arthritis care for nurses and rehabilitation therapists</li> <li>• Develop a process to ensure continuing competency of arthritis allied health professionals</li> <li>• Develop resources and infrastructure to mentor the next generation of arthritis health professionals and researchers</li> </ul>

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creating challenges for arthritis care, especially since demand for services is expected to increase in the next 20 years<sup>12</sup>. Many countries are beginning to develop new models for arthritis management that may involve information technology for health record keeping and patient monitoring, patient-initiated care, and extended roles for allied health professionals<sup>7</sup>. However, the effect of these new models has been limited since most research is focused on the short period around the time of diagnosis. Knowledge is incomplete regarding effective methods to identify people with early symptoms of joint diseases and about strategies to coordinate longterm management. A research priority identified at CARE III therefore is to develop and evaluate innovative methods for identifying individuals with arthritis in the community and facilitating timely access to treatment and longterm monitoring.

#### **To adapt and implement effective service models to address local needs**

A number of healthcare delivery models have been successful in managing rheumatoid arthritis (RA): In Europe these include the multidisciplinary team model<sup>13,14</sup>, the shared-care model involving rheumatologists and primary care physicians<sup>15,16</sup>, nurse-led clinics<sup>17–21</sup>, and the patient-initiated care model<sup>22</sup>. Canada has been a leader in advancing the primary care model through the Getting a Grip on Arthritis education project<sup>23</sup> and in developing extended roles among rehabilita-

tion professionals<sup>24–28</sup>. Most of these health service models have demonstrated effectiveness in a specific context, but they have not been tested in other regions or settings.

Since each care environment has unique needs and challenges, decisions to adopt a model should be based on the suitability of the model for local use and by the likelihood of successful implementation. For this reason, CARE III recommends well-designed needs assessments and environmental surveys, as a priority for future research. This should be followed by appropriate support for local implementation.

#### **To understand factors related to successful team care**

Multidisciplinary team care is considered the gold standard for management of RA<sup>13</sup>; however, the evidence for team care is based mainly on European studies with limited information about the components of teams. As such, it is difficult to reproduce the same team structure in other countries or settings. Moreover, to our knowledge, there is no study examining the local sustainability of rheumatology teams. Vliet Vlieland, *et al*<sup>11</sup> have pointed out that the poor knowledge about components in the “team care box” has hindered our ability to develop effective teams in the past 15 years. To this end, CARE III recommends that future research focus on the process of developing a successful rheumatology team by examining the effect of different communication models, identifying health disciplines that are equipped or can be

“retooled” to provide effective interventions, and understanding the influence of “place” (i.e., hospital, clinic, home, virtual place) on the delivery of care.

### **To match patients’ needs with appropriate care models**

With the success of new pharmacological treatments and education programs, people with inflammatory arthritis are now encouraged to take a more active role in managing their health. Since patients’ conditions may vary throughout the course of disease, it is unrealistic to believe that any single model of care is appropriate for all patients at all times. This leads to the question about the timing and the appropriate use of multidisciplinary teams versus other less intensive care models.

*Does everyone with arthritis need a team?*<sup>11</sup> To address this question, we need to understand the characteristics of individuals who achieve the best outcome under a specific health service delivery model. The next challenge will be to develop comprehensive healthcare delivery systems that meet the needs and preferences of patients with various forms of arthritis and to evaluate them with respect to effectiveness, costs, patient satisfaction, and applicability at various stages of disease. One useful source of information is the clinical setting, where individual characteristics, as well as disease and health outcomes and use of health services, are collected longitudinally. Exploratory analyses of this information can be useful for generating sound hypotheses for future research about matching patients’ needs with service models.

### **To design new or improve existing outcome measures for participation and quality of life**

Previous CARE conferences have recommended sound theoretical frameworks and the concept of patient perspective to guide selection of outcome measures in research of team care and nonpharmacological treatments<sup>1,2</sup>. At CARE III, development of a core set of outcome measures for care research was generally supported by participants; however, challenges need to be recognized. For example, we currently do not have standardized outcome measures that adequately assess individuals’ involvement in life roles, called participation, as defined in the International Classification of Functioning, Disability and Health<sup>29</sup>. Some quality of life measures, such as the Medical Outcome Study Short Form-36, include components on life roles; however, since there are conceptual differences between participation and quality of life, these existing measures may not be sufficient to capture all domains pertinent to participation<sup>9</sup>. Further understanding about the concept of participation will contribute to development of adequate outcome measures, which are the building blocks of a core set of measures for care research.

### **To foster partnerships in sharing research evidence**

There is a growing awareness that research findings and clinical guidelines are not making their way into clinical practice

and policy making. In the CARE III online survey, we found potential gaps in physicians’ recommendations of nonpharmacological interventions and in patients’ perception about treatment effectiveness<sup>4</sup>. The traditional model of disseminating evidence through publication in peer-reviewed journals on completion of a research project may not be practitioners’ preferred method for acquiring evidence-based information<sup>30</sup>. The new trend is to incorporate a knowledge translation and exchange strategy in research projects and start planning activities early with appropriate stakeholders. However, we currently know very little about the characteristics of an effective stakeholder, their roles in research, and the appropriate timing of their involvement<sup>8,31</sup>. Also, it is unclear whether funding agencies should include patients/nonresearchers in grant review panels and what their roles should be in the deliberation process. Future research needs to address these important and fundamental questions in order to facilitate meaningful consumer partnerships in research.

### **To address needs for training and quality assurance**

The disparity between supply and demand in health human resources<sup>32-34</sup> can lead to delayed diagnosis and delayed access to effective treatments and followup. CARE III initiated the discussion around strategies to ensure high quality and timely care, some of which included extending and streamlining roles of nursing and rehabilitation professionals. A few questions concerning health professional training and continuing education deserve further consideration:

- What should be included in the core and advanced arthritis curricula for nurses and rehabilitation therapists?
- How do we ensure continuing competency among these health professionals?
- What kind of resources and infrastructure are needed to mentor the next generation of arthritis health professionals and care researchers?

## **CONCLUSION**

Building on the recommendations of the first 2 CARE conferences, CARE III has shifted the focus away from a single disease (i.e., rheumatoid arthritis) and a single model of care (i.e., multidisciplinary team care) to examine a number of emerging service models in a variety of arthritic diseases. We believe that advances in research and education can offer solutions to narrow gaps in health human resources and arthritis care. It is our hope that funding agencies in North America and Europe will consider investing in these priorities, which will ultimately contribute to better and more efficient care for individuals living with arthritis.

## **ACKNOWLEDGMENT**

The Co-chairs thank the following contributors:

*CARE III International Steering Committee:* Catherine Backman, Ann Bremander, Jackie Hill, Maura D. Iversen, Ingemar Petersson, and Christina Opava.

*Members of the International Conference Planning Committee:* Thea Vliet

Vlieland (Leader of Model of Care team), Maura Daly Iversen (Co-leader of Research Design team), Ingemar Petersson (Co-leader of Research Design team), Catherine Backman (Leader of Outcome Measure team); Ann Bremander, Christina Opava, and Jacqueline Hill.

We also thank the following individuals for facilitating local conference activities, including the CARE III online patient survey: Elizabeth Badley, Crystal Mackay, Ann Qualman, Sydney Lineker, Dorcas Beaton, and Lucie Brosseau. For administrative support we thank Valerie Bibb and Jean Rookwood, and Helena Axler for facilitating the conference. Finally, we thank Sherra Solway and Annette Wilkins for their excellent work in preparing the detailed conference proceedings on which this article is based.

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